Patient Perspectives: Chronic Pain

NIH HEAL - Managing Chronic Pain in Individuals with Co-Occurring OUD, and Other Psychiatric Disorders
June 1-2, 2020

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Co-Founder & Director

www.ChronicPainResearch.org
CHRONIC PAIN & OPIOID USE DISORDER

... EPIDEMIC OF CHRONIC ILLNESS
America Has Become a Nation of Chronic Disease

CHRONIC DISEASES IN AMERICA

6 in 10 Adults in the US have a chronic disease

4 in 10 Adults in the US have two or more

THE LEADING CAUSES OF DEATH AND DISABILITY
and Leading Drivers of the Nation’s $3.5 Trillion in Annual Health Care Costs

HEART DISEASE, CANCER, CHRONIC LUNG DISEASE, STROKE, ALZHEIMER’S DISEASE, DIABETES, CHRONIC KIDNEY DISEASE
90% of the nation’s $3.5 trillion in annual health care expenditures are for people with chronic and mental health conditions.

... but ... with few exceptions ... our health care system hasn’t adapted
Current “Hyper Focus” on 2 Numbers

**VAS**
Pain Severity Score

**MME**
Morphine Milligram Equivalent

![VAS Pain Severity Score](image)

![MME Morphine Milligram Equivalent](image)
What Do These Numbers Really Tell Us?

= MME 60 =

= VAS 8 =

THERE'S MORE TO THE STORY
Chronic Pain Does Not Exist in a Vacuum – Rather a Complicated Messy Environment (aka a “Person”)
Complexity of Chronic Pain

Experience is Highly Individual

Multiple Chronic Conditions

Multiple Pain-Related Conditions

Bio-Psycho-Social-Spiritual

Multiple Pain Conditions
What is IMPORTANT and CLINICALLY MEANINGFUL to patients?
Public Meeting on Patient-Focused Drug Development for Chronic Pain
July 9, 2018
“Input underscore the diversity of experiences with chronic pain ... the complexity of selecting an appropriate treatment ... and the broader challenges individuals face in accessing care, treatment, and support.”
The health effects of chronic pain are pervasive and wide ranging.
Chronic pain affects ALL aspects of individuals’ lives.
Patients reported difficulty in achieving pain relief. Effective pain management requires a multidisciplinary approach tailored to the individual.
U.S. Pain Collaborative

• **Collaborative project among 6 patient advocacy organizations:**
  – Support from VOZ Advisors & Grunenthal

• **Goals:**
  – What questions do chronic pain patients want their provider(s) to ask them?
  – What is the discrepancy between what providers ask and what patients want to be asked?

• **Survey Information:**
  – n~1500 patients aged 18-80+ years
  – 2/3 of respondents lived with chronic pain for 10+ years
  – Variety of conditions represented: CRPS, back pain, arthritis, migraine, fibromyalgia, vulvodynia, IC
  – 30% seeing 3+ providers (60% managed by primary care, 50% pain medicine/management)

[Link to the survey information]

U.S. Pain Collaborative Survey Findings

- Pain Treatment Goals:
  - % of Patients Who Want Provider to Ask: 74%
  - % of Patients Whose Provider Asks: 26%

- Ability to Cope:
  - % of Patients Who Want Provider to Ask: 74%
  - % of Patients Whose Provider Asks: 27%

- Ability to Concentrate & Process Information:
  - % of Patients Who Want Provider to Ask: 64%
  - % of Patients Whose Provider Asks: 18%

- Level of Support from Family, Friends & Co-workers:
  - % of Patients Who Want Provider to Ask: 61%
  - % of Patients Whose Provider Asks: 18%

- Social Functioning:
  - % of Patients Who Want Provider to Ask: 62%
  - % of Patients Whose Provider Asks: 21%
U.S. Pain Collaborative Survey Findings

- % of Patients Who Want Provider to Ask
- % of Patients Whose Provider Asks

<table>
<thead>
<tr>
<th>Category</th>
<th>% of Patients Who Want</th>
<th>% of Patients Whose Provider Asks</th>
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<tbody>
<tr>
<td>Level of Energy/Fatigue</td>
<td>77</td>
<td>38</td>
</tr>
<tr>
<td>Ability to Work</td>
<td>63</td>
<td>25</td>
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<tr>
<td>Level of Stress</td>
<td>73</td>
<td>36</td>
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<tr>
<td>Ability to Perform Daily Activities</td>
<td>78</td>
<td>45</td>
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<tr>
<td>Mood/Outlook</td>
<td>68</td>
<td>36</td>
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<tr>
<td>Amount/Quality of Sleep</td>
<td>79</td>
<td>52</td>
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U.S. Pain Collaborative – Other Major Findings

- Only 29% felt it was important for their pain to be evaluated on a numeric scale.
- >90% indicated changes are needed to the way providers evaluates chronic pain.
- >50% stated that they would like to work with their provider to decide which questions about chronic pain and which pain measurements are best for them.
- Evaluated a number of established pain evaluation assessments (BPI, VAS, Global Pain Scale, McGill Pain Questionnaire, QOL scale, West Haven-Yale Multidimensional Pain Inventory, etc.).
  - 45% of respondents indicated they were “somewhat useful” but did not fully capture the chronic pain experience.
  - Of the scales, McGill best captured the chronic pain experience (although still incomplete).
<table>
<thead>
<tr>
<th>OLD</th>
<th>NEW</th>
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<tbody>
<tr>
<td>Sole/major focus on pain severity/frequency in isolation</td>
<td>Complex, multi-system disorder - with focus on function/QoL</td>
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<tr>
<td>Disease Model</td>
<td>Wellness Model</td>
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<td></td>
<td>- Focus on understanding factors related to how one can “live well” with chronic illness</td>
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<td></td>
<td>- Brain health</td>
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<td>Sole/major focus on risk factors and factors that can worsen chronic pain</td>
<td>Equal focus on risk/worsening factors AND protective/resilience factors</td>
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<tr>
<td>Focus on “how bad” things are (i.e., how bad has your pain been?)</td>
<td>What are your goals? What is chronic pain stopping you from doing that is important to you? How can we work towards changing that?</td>
</tr>
<tr>
<td>“One size fits all” approach decided upon by clinician only</td>
<td>Individualized, patient-centered approach that assesses all conditions/factors that influence (or are influenced by) chronic pain</td>
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Thank you!

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